

# **VISUAL IMPAIRMENT IN SCOTLAND**

A guide for funders

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THE  
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# INTRODUCTION

## Setting the scene

Significant sight loss affects around 188,000 people in Scotland.<sup>1</sup> This figure is set to double by 2031 as a result of the aging population, and because of the increase in health conditions associated with visual impairment—such as obesity and diabetes.<sup>2</sup> Sight loss can be devastating for those affected—many people end up losing their independence, feeling isolated, and becoming depressed.

With the right support, visually impaired people can play a full and active part in Scottish society. Unfortunately, this kind of support is becoming increasingly over-stretched.

## The purpose of this report

Independent funders can make a big difference to the lives of visually impaired people in Scotland. This report is a guide for those who wish to do so, and has four key aims:

- to explain the context for the vital work of charities and funders working on visual impairment in Scotland;
- to outline the priority needs of people with visual impairment in Scotland;
- to identify solutions, gaps in funding, and opportunities for funders; and
- to examine the role of independent funders, setting out some questions that funders can ask themselves when prioritising their activities.

This report is the product of desk research and interviews with charities, funders and academics working on visual impairment issues in Scotland. We hope that the frameworks included will enable funders to think through how they can have the greatest impact on the lives of people with visual impairment in Scotland.

While it is written with funders in mind, this report will also be of interest to: charities that work within the visual impairment sector; policymakers; academics; and the general public; including people with sight loss and their carers.

# THE LANDSCAPE OF VISUAL IMPAIRMENT IN SCOTLAND

In this chapter we define visual impairment, and then explore the key trends that provide the backdrop to improving the lives of visually impaired people in Scotland.

## Definitions and prevalence

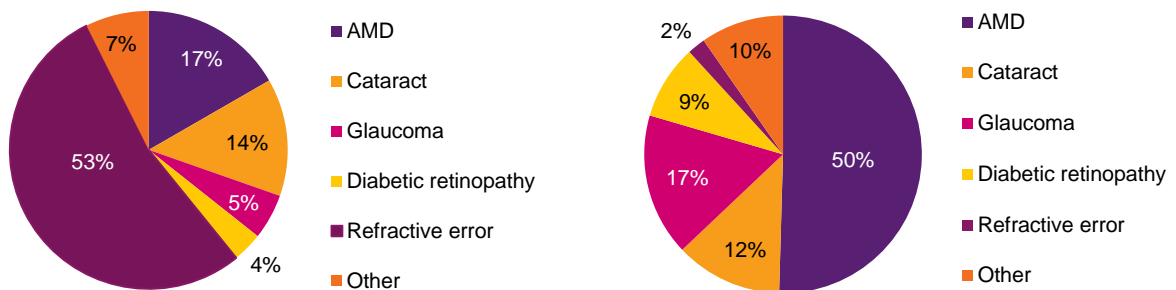
### Defining visual impairment

Visual impairment occurs when a person has sight loss that cannot be corrected by using glasses or contact lenses. It means that at least one function of the eye or visual system is limited. The most common impairments are of visual acuity (sharpness or clarity of vision), visual fields (the ability to see around the edge of your vision while looking straight ahead), contrast sensitivity, and colour vision.<sup>3</sup>

### Causes of visual impairment

Visual impairment can be the result of degenerative conditions, congenital conditions, trauma or disease. The most common causes of sight loss in adults are age-related macular degeneration (AMD), refractive error, cataracts, glaucoma, diabetic retinopathy, and inherited eye diseases (see Figure 1 and Figure 2).<sup>4</sup>

Figure 1: Main causes of sight loss in adults in the UK    Figure 2: Main causes of blindness in adults in the UK



Source: RNIB (2013) *Sight Loss UK 2013*.

For children, the three most common causes of severe visual impairment and blindness are cerebral visual impairment, disorders of the optic nerve, and disorders of the retina.<sup>5</sup>

Sight loss can be a 'hidden disability' for people with other diseases or complex needs. For example, around 60% of stroke survivors experience vision problems after their stroke, but only 9% of occupational therapists working in Scottish stroke inpatient services report having access to a protocol for post-stroke visual impairment.<sup>6</sup> Sight problems may also be undiagnosed for people with complex needs such as dementia<sup>7</sup> or a learning disability<sup>8</sup>. This is because they may not be aware of their own visual impairment, and others around them may not realise that their behaviours are symptoms of a sight condition.<sup>9</sup>

### The prevalence of visual impairment in Scotland

Significant sight loss affects around 188,000 people in Scotland.<sup>10</sup> Its prevalence increases with age: three out of every four people with sight loss in Scotland are aged over 65.<sup>11</sup> Most of the rest are working-age adults: there

are over 8,000 registered blind or partially sighted people of working age in Scotland (though this is likely to be an under-estimate).<sup>12</sup> There are also around 2,500 children and young people with a visual impairment in Scotland.<sup>13</sup>

## Trends affecting visual impairment in Scotland

The landscape of visual impairment in Scotland is rapidly evolving. Here we outline some key trends: significant demographic shifts, important policy changes, and opportunities presented by new technology.

### Demographic shifts

The number of people living with sight loss in Scotland is expected to double by 2031 to almost 400,000 people.<sup>14</sup> This is largely because the population is ageing: between 2010 and 2035, the percentage of the population aged 75 and over is projected to increase by a staggering 82%—significantly higher than the equivalent figure for the rest of the UK.<sup>15</sup> There is also a high incidence of health conditions such as smoking and obesity, both of which can double the probability of sight loss. For example, adult smoking rates in Scotland (25%) are consistently higher than in England (20%).<sup>16</sup> The number of Scottish people with Type 1 or Type 2 diabetes increases by around 10% every year, and diabetic retinopathy is now the single biggest cause of sight loss among Scots of working age.<sup>17</sup>

The prevalence of sight loss is putting pressure on healthcare systems. Up to one in six outpatient appointments at Scottish hospitals are for eye-care.<sup>18</sup> The rise in availability of new treatments (notably for AMD) has not been matched by expansions in capacity, and waiting times have increased. Caring for people with visual impairment will become increasingly expensive as the number of people requiring specialist services rises. Excluding the cost of new expensive wet AMD treatments, eye diseases cost the NHS and the public sector in Scotland at least £194m a year, plus £434m more in terms of broader costs to the economy and to society.<sup>19</sup>

### Policy changes

The experts we interviewed all agreed that, in an era of public sector austerity, the role of the state in visual impairment is changing rapidly. Across the UK, the state is playing an ever smaller role in social care and welfare provision. While these changes are happening later in Scotland than in England, interviewees said that last year was characterised by a noticeable retreat of the state. Local authorities are seeing significant cuts to their budgets at a time when demand is increasing. Eligibility criteria for social care are being set ever higher, leaving many people with sight loss unable to access the services they need. Councils are also tightening procurement rules and putting contracts out to tender, leading to considerable uncertainty for small visual impairment charities. The result, according to one expert, is a *'deterioration of statutory services'* for visually impaired people.

Against this backdrop of cuts, there are some positive policy developments. Eye health is being pushed onto the Government's radar, and the sector is coming together and speaking with one voice to a degree that has not been seen before. Some of the key developments in recent years include the Scottish Vision Strategy, the See Hear strategy, and the 'Getting it right for every child' approach:

#### The Scottish Vision strategy

This cross-sector framework to improve provision for eye health and sight loss<sup>20</sup> aims to ensure that: everyone in Scotland knows how to look after their eyes; that everyone with an eye condition receives timely treatment and, if permanent sight loss occurs, there are early and appropriate services and support; and that Scotland is a society in which people with sight loss can fully participate. While the aims of the Scottish Vision Strategy are widely supported, one interviewee told us that it remains *'an aspirational piece of work that is yet to be widely adopted in Scotland'*.

## The See Hear strategy

Launched by the Scottish Government in 2014, this strategy raised the profile of sensory impairments.<sup>21</sup> Most notably, it called for more consistency in how services are planned and commissioned across Scotland's 32 local authorities, each of which had to set up local implementation groups. It also called for a move towards joint sensory services for those experiencing sight and/or hearing loss. People we spoke with had some doubts about whether this was always the most effective approach for their beneficiaries. Some also cautioned that the long-term impact of the See Hear strategy could be limited in challenging economic times.

## 'Getting it right for every child' (GIRFEC)

This approach—enshrined in law by the Children and Young People Scotland Act 2014—states that all children, including those with a visual impairment, should be supported to address their well-being needs throughout their lives.<sup>22</sup> The GIRFEC principles were built upon by the 2012 Doran Review, which examined learning provision for children with complex additional support needs, including visual impairment.<sup>23</sup> In recent years, there has been a presumption that these children should be educated in mainstream schools except under exceptional circumstances.<sup>24</sup> The Doran Review uncovered problems including a lack of resources, limited staff expertise, poor staff attitudes, bullying and social isolation. In response to these issues, the Doran Review recommended that the Scottish Government should develop a national planning and commissioning process for education services to meet children's needs.

## Opportunities presented by new technologies

New technologies have the potential to transform the lives of visually impaired people. Appropriate lighting and adaptations to everyday objects can help people with sight loss to cook safely and use domestic appliances like washing machines. Modern-day computers, tablets, e-readers and smartphones come with built-in accessibility features, which can be supplemented by assistive technology and commercial hardware, such as braille displays or high-visibility keyboards. These resources make it easier for visually impaired people to participate in a wide range of activities—from accessing information to communicating.

New technologies can also pose challenges. Older people in particular can struggle to keep pace, and visually impaired people of all ages can be disadvantaged by new domestic technologies, such as the use of flat screens to control ovens or central heating. One of our interviewees pointed out that *'tech is moving fast, so barriers to entry will remain even as people become more familiar.'*

# PRIORITY NEEDS

Everyone with sight loss has unique needs, assets and priorities. But there are some common themes when it comes to what contributes to their welfare, and current gaps in provision. In this chapter, we outline the priority needs of visually impaired people at different stages of their lives.

## Priorities of people with visual impairment

In 2011, a UK-wide consultation with blind and partially sighted people sought to understand which issues are most important to them. This resulted in ten ‘Seeing it my way’ outcomes, which can be used as the starting point for understanding the priority needs of visually impaired people across Scotland.<sup>25</sup> The ten outcomes are:

- I understand my eye condition and the registration process.
- I have someone to talk to.
- I can look after myself, my health, my home and my family.
- I receive statutory benefits and information and support that I need.
- I can make the best use of the sight I have.
- I can access information making the most of the advantages that technology brings.
- I can get out and about.
- I have the tools, skills and confidence to communicate.
- I have equal access to education and lifelong learning.
- I can work and volunteer.

The ‘Seeing it my way’ outcomes have been written into the *Scottish Vision Strategy (2013–18)*<sup>26</sup> with the aim to make them a reality across Scotland. They are intended to support people to live independently regardless of their age, ethnicity, extent of sight loss, other disabilities, and location.

Experts emphasise that these needs vary widely for different age groups. For example, older people who lose their sight are at a particularly high risk of facing difficulties getting out and about, while young children may struggle to develop communication skills. Based on our research and interviews, we have divided visually impaired people into four age groups and identified the priority ‘Seeing it my way’ outcomes for each cohort (Figure 3). The remaining outcomes relate to social systems and support structures that affect all age groups, from the registration process to technology.

The rest of this chapter provides more information about the distinct needs of each age group as well as the systems that affect all age groups. Rather than attempting to provide an exhaustive list, we highlight needs that are particularly acute or that affect large numbers of people in each cohort. We have expressed the needs in terms of the ‘Seeing it my way’ outcomes—in the words of visually impaired people themselves.

Figure 3: Priority needs for people with visual impairment



**Social system and support structure needs across all age groups**

**Priorities for different age groups**

**Pre-school children**

For most children, around 80% of what they learn occurs through vision.<sup>27</sup> Children who are born blind or partially sighted therefore face particular challenges to physical and social development—challenges that are often compounded by additional conditions, such as neurological impairments or conditions associated with premature birth.<sup>28</sup>

**'I have the tools, skills and confidence to communicate'**

Visual impairment changes the dynamics of children's early communication and social development. Eye contact enables babies to interact with their caregivers and build an emotional connection.<sup>29</sup> Without appropriate support to develop alternative communication techniques, caregivers can struggle to interact with their visually impaired babies. Looking at faces helps infants to develop their understanding of the world around them and stimulates *'the growth of the social, emotionally intelligent brain.'*<sup>30</sup>

As children get older, they learn life skills and social norms by observing and imitating adults, as well as interacting with their peers. Young blind children in mainstream early learning settings have fewer opportunities to acquire language and social skills through free play. Without the right support to interact with their peers and their surroundings, their learning can be hindered and their understanding of the world restricted.

**School-aged children**

Many visually impaired children struggle to reach their full potential at school. This is reflected in an attainment gap between them and their sighted peers. School leavers with a visual impairment achieved an average tariff score of 241 in 2012/2013, compared with 439 for pupils without additional support needs.<sup>31</sup> These figures are complicated by the fact that 60–70% of children with sight problems have additional disabilities, usually linked to



neurological conditions.<sup>32</sup> The Scottish Sensory Centre argues that visually impaired children with no other support needs are *'achieving only slightly less'* than their peers in academic terms, but that they are leaving school with poor mobility and independent living skills.<sup>33</sup>

### **'I have equal access to education and lifelong learning'**

In 2015, the Scottish Parliament's Education and Culture Committee raised concerns that some pupils with sensory impairments are not receiving the support they need in mainstream schools.<sup>34</sup> Experts point out that there is patchy provision in Scotland of qualified teachers of the visually impaired (QTVI) and specialist workers for children's habilitation.<sup>35</sup> The Visual Impairment Network for Children and Young People (VINCYP) is undertaking a major mapping exercise that has uncovered significant gaps in support services and training.<sup>36</sup>

Visually impaired students face particular difficulties in times of transition. As children move from primary to secondary school, their learning can suffer as their classroom support is disrupted. Moving schools can also be *'hugely emotional'* as routines and friendship groups are disrupted.<sup>37</sup> As young people transition to further or higher education, they experience more upheaval. They often have to return equipment that they have been using for years and may wait months for new equipment to arrive. In these circumstances, many fall behind or drop out of the system altogether. Only 20% of school leavers with a visual impairment progress to higher education, compared with 40% of those with no additional support needs.<sup>38</sup> It is no surprise that the Doran Review found *'deep anxieties and concerns about transition'* among children and their parents.<sup>39</sup>

### **Working-age adults**

Working-age adults with sight loss may be considered less vulnerable than older and younger groups, and they often receive less specialist support. Yet they still experience significant issues and face barriers to their well-being. More than two in five struggle to make ends meet—twice as many as those with no impairment.<sup>40</sup>

### **'I can work and volunteer'**

Our interviewees highlighted access to work as the priority issue for this group. Two thirds of working-age people who are registered as blind and partially sighted in Scotland are not in paid employment.<sup>41</sup> Deteriorating vision can mean that parts of a person's job become impossible, and employers may be reluctant to rearrange roles or make adaptations. Many *'cannot imagine a job being done by a blind person'*. This lack of creativity and flexibility force many people to give up work.

### **'I can look after myself, my health, my home and my family'**

Sight loss has a profound emotional and social impact, with repercussions for people's sense of self and how they relate to others. Changes to identity can particularly affect adults who are forced to give up their job or who find that they are no longer able to look after their family. People with a visual impairment are six times as likely to feel depressed as those with no impairment, and 11 times as likely to feel that their confidence is low.<sup>42</sup>

The emotional journey of people with acquired sight loss is outlined in Mhairi Thurston's five-stage transition to blindness model, shown in Figure 4.

**Figure 4: Transition to blindness model, adapted from Thurston (2010)<sup>43</sup>**



In the early stages of this transition, people resist their diagnosis and are not able to engage with it emotionally. The critical *'point of impact'* can come weeks or months after the initial diagnosis, or it may not happen until

decades later, for example, when their partner dies. At this stage, people have to deal with the loss that visual impairment brings—for instance, it may mean giving up on their future hopes and dreams of travelling the world or seeing their children grow up. As people engage with physical rehabilitation, they must learn not only to cope with the identity that society gives them, but also to cope with their own transformed perception of themselves. With the right emotional support, some people reach the final stage of accepting their sight loss and embracing their new identity.

## Older people

*'Visual impairment in older people is often simply accepted as an issue of older age (and sometimes misinterpreted as dementia), so it gets buried. We need to make sure the elderly are supported.'*

**Richard Hellewell, Chief Executive, Royal Blind and Scottish War Blinded**

This is the single largest age group affected by visual impairment. One in five people aged 75 or over are living with sight loss.<sup>44</sup> This fact alone makes them a priority group for support. But the experience of visual impairment can be particularly challenging for this group as it often sits alongside other health issues or comorbidities.<sup>45</sup> Moreover, older people and healthcare professionals often consider deteriorating vision to be a natural part of ageing, rather than a condition requiring a response.

### **'I can get out and about'**

Sight loss is associated with poor balance and a greater risk of falls. When combined with the frailty of old age, it leads to people becoming increasingly housebound. Only around 30% of people over 75 with sight loss feel able to go to the corner shop.<sup>46</sup> This can lead to what one charity leader described as a *'total downward spiral'* impacting on all aspects of people's lives, from their mental health to their ability to access nutritious food. In remote areas of rural Scotland, these issues are exacerbated by difficulties accessing public transport and the long distances to travel to reach services.

### **'I can make the best use of the sight that I have'**

Many people with AMD and other forms of partial sight loss are not making the best use of the sight they have. Early intervention to teach rehabilitation and coping techniques can help people to adapt as their sight deteriorates—far better than trying later on to re-incorporate activities into their routine that they previously decided were off limits. Yet time and again, experts told us of a shortage of specialist rehabilitation workers in Scotland to help people to adapt practically to their visual impairment. In recent years, experienced staff have been leaving as cuts kick in, and there has been no course in Scotland through which new rehabilitation workers can be trained. This situation may change in the near future as Glasgow Caledonian University is planning such a course.<sup>47</sup>

### **'I have someone to talk to'**

The loneliness that stems from isolation is the *'the most distressing factor of all'* for older people with sight loss, according to our expert interviewees. Many of these older people lose contact with friends and social groups as they increasingly stay away from activities outside the home. Social situations can become more difficult if people have trouble recognising familiar faces, and a lack of routine social interaction can escalate into loneliness, depression, and a sense of worthlessness.<sup>48</sup>

## Social systems and support structures

*‘There’s a flat-out equality issue in relation to how people with visual impairment are treated.’*

John Paterson, Chief Executive, Scottish Council on Visual Impairment (SCOVI)

Social systems and structural concerns—from difficulties accessing information to lack of appropriate technology—underpin many of the issues facing visually impaired people of all ages.

### **‘I understand my eye condition and the registration process’**

Experts highlight how important it is for individuals to receive information about their eye condition throughout their ‘care pathway’.<sup>49</sup> This includes information and advice in relation to prevention, assessment, treatment, registration, and referral routes for further support.<sup>50</sup> Between 50% and 70% of sight loss in older people, for example, is thought to be preventable or treatable.<sup>51</sup> Information about how to manage a progressive condition can be life-changing.

Registering sight loss triggers a local authority needs assessment, which can help people to access social care, financial support, aids and equipment. Yet as few as 23–38% of eligible people are actually registered.<sup>52</sup> While moves are underway to review the formal registration system in Scotland, charities are concerned that there will be no money available to update their systems or increase the number of registrations.

### **‘I receive statutory benefits and information and support that I need’**

Visually impaired people find it difficult to access information and support for a variety of reasons. There is a widely held view that people with sensory loss may not have benefited from the Equalities Act 2010 to the same extent as others.<sup>53</sup> For example, less than 7% of books are published in braille, large print and audio formats.<sup>54</sup> The Royal National Institute for Blind People (RNIB) Scotland has found that only 10% of correspondence from health services to blind and partially sighted people is received in their preferred reading format.<sup>55</sup> This leads to people experiencing a loss of autonomy and privacy concerning their health data.

A similar picture emerges around access to statutory benefits. The Scottish Vision Strategy supports the provision of benefits that take into account the additional financial costs arising from blindness and sight loss.<sup>56</sup> These benefits may include Daily Living Allowance (for people aged under 65), Attendance Allowance (for those aged over 65), Carers Allowance, Housing Benefit, Council Tax Benefit, and free bus travel. In practice, high eligibility thresholds, low levels of registration, and the burden of paperwork required to access benefits mean that many people are missing out.

### **‘I can access information making the most of the advantages that technology brings’**

Significant barriers prevent visually impaired people from taking advantage of the opportunities presented by technology. Access to equipment and training is patchy across Scotland. One interviewee said that it was an *‘injustice’* that hearing aids are available on the NHS, but reading aids are not. Many local authorities have specialist equipment available for loan to those who meet certain need criteria, but resources are stretched thinly and the quality of assessment and training is variable.

Even when the correct equipment is in place, barriers remain. In 2015, an inquiry by the Scottish Parliament’s Education and Culture Committee found that *‘basic technological failures mean some pupils are not able to access learning materials or make use of their assistive technologies in school.’*<sup>57</sup> School intranets may not support pupils’ Braille note-taking devices, while network policies can block access to useful apps or special support websites. There is often no contingency for equipment breakdown, and teachers may struggle to meet their students’ technology needs.<sup>58</sup>

# PRIORITY SOLUTIONS

There are plenty of opportunities for independent funders who want to improve the lives of visually impaired people in Scotland. In this chapter, we highlight some general principles of good practice for funders and charities to consider, followed by some solutions that would benefit from investment.

## Principles of good practice

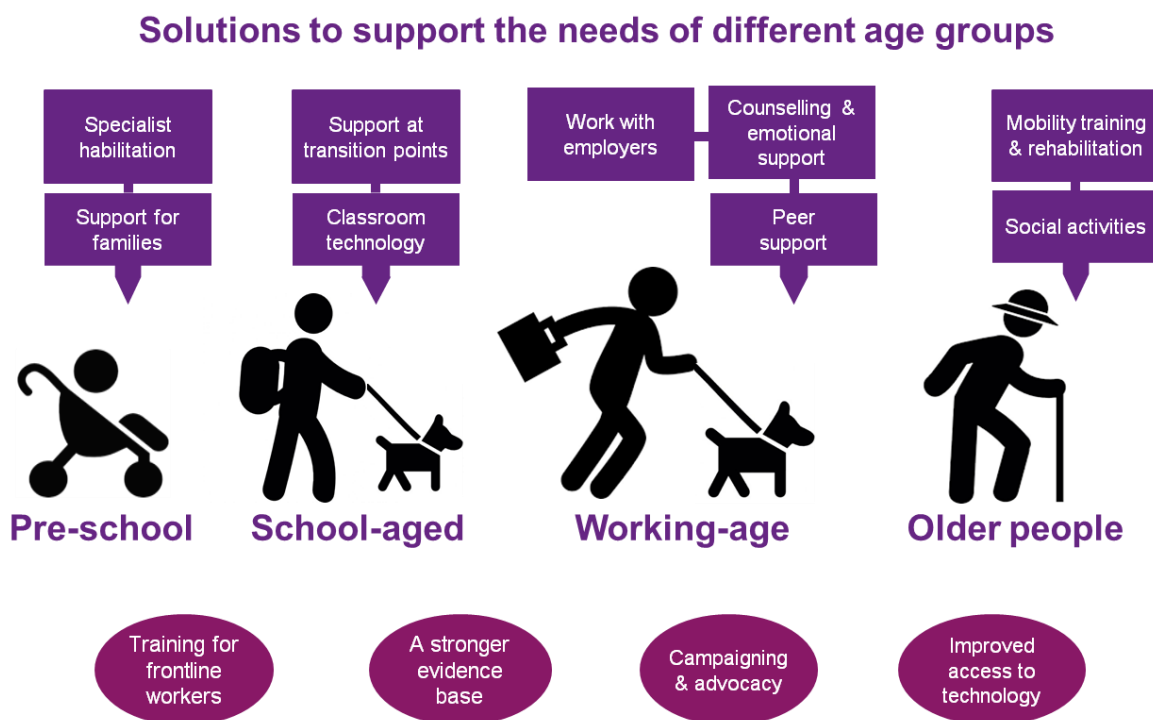
In the field of visual impairment, the solutions with the greatest impact adhere to three principles:

- **Specialist:** They are delivered by specialist staff who are able to provide high quality assessment and support that is tailored to the needs of people with visual impairment.
- **Person-centred:** They are focused on the whole person and tailored to meet that person’s need.
- **Social:** They build in elements of social interaction and peer support.

## Priority solutions

Figure 5 highlights priority solutions that are particularly relevant to the four age groups identified in this report, plus solutions that relate to social systems and support structures affecting visually impaired people of all ages.

Figure 5: Priority solutions to meet the needs of people with visual impairment



## Solutions for different age groups

We have prioritised solutions for each age group based on both the evidence of their effectiveness and the potential for independent funders to make an impact.

### Pre-school children

#### Specialist habilitation

Specialist habilitation from birth is the priority for children who are born with visual impairment. Experts emphasise the importance of early intervention in this critical development window. Unfortunately, statutory provision does not meet these needs: there is some input from health visitors who have limited experience of visual impairment, but in many areas there is no specialist support until a child is two years old.<sup>59</sup> Some charities provide specialist habilitation support that goes beyond what the state funds. For example, Visibility (which works in west Scotland) invited Daniel Kish, an expert in human echolocation from California, to train its outreach staff in this innovative technique a few years ago.<sup>60</sup> Echolocation enables people to navigate using tongue clicks, and admirers say that it is a particularly effective way of helping young children to gain confidence and independence.

#### Support for families

Family support in the early years can empower parents to meet the needs of children who have sight loss. Experts argue that there needs to be a significant shift in the type of family support that professionals provide, with a greater emphasis on helping families with visually impaired young babies, rather than waiting until children are older.<sup>61</sup> By working with individual families or through sensory play groups, specialists can teach parents how to provide practical and tactile experiences to help their blind child to become more mobile and understand the world around them.<sup>62</sup> The best services go beyond functional support to promote *'a positive, aspirational approach to managing the disability and potential barriers that will emerge'*.<sup>63</sup> For example, Visibility and RNIB Scotland have just launched a multi-year joint initiative to deliver targeted emotional and practical support to children and families, as well as signposting to other services.

### School-aged children

#### Support at transition points

Charities can target their support for schoolchildren around the difficult transitions from primary to secondary school, or from school to university. Critically, this includes providing support that goes beyond the academic curriculum to cover social skills, mobility, and independent living skills. For example, Royal Blind School provides mobility and life skills training as part of its specialist curriculum for visually impaired children.<sup>64</sup> Other charities could provide this kind of support at times of transition in mainstream schools.

#### Classroom technology

In the classroom, creative use of new technologies can motivate visually impaired students and greatly enhance their learning experience. The Scottish Association for Visual Impairment Education (SAVIE) highlights examples including pupils' laptops directly connected to a teacher's live interactive whiteboard, or iPads linked to Brailenote through Bluetooth, so that any book available electronically can be read in Braille.<sup>65</sup> The Doran Review observed the *'pride and confidence'* of visually impaired pupils using communication aids.<sup>66</sup> Students who have access to these technologies find it easier to socialise and feel more included in the class's activities. Equipment loans for pupils moving to a new school—such as the loans provided by RNIB Scotland—can have a huge impact on children who would otherwise face an anxious time waiting for new equipment to arrive.

## Working-age adults

### Work with employers

Work with employers is a priority for supporting visually impaired people to access employment. Charities can encourage employers to provide support, aids and adaptations so that people do not have to give up their job when they lose their sight. For example, RNIB Scotland provides advice for employers on how best to support workers with sight loss, including providing information in alternative formats, such as audio or braille. Experts emphasise the importance of employer mindsets and the need for solutions that challenge misconceptions.

### Peer support

Working-age people with visual impairment can also benefit from interventions to increase their confidence and raise their awareness of what is possible. Research from the US found that having positive role models who are themselves blind improves outcomes for visually impaired people seeking education, training or employment.<sup>67</sup> Peer support groups—like Visibility’s ‘Someone Like Me’ project for those aged 18–55—provide space for people to meet others going through similar experiences, and explore worries and issues. This is particularly important because younger people can feel excluded from social activities for the visually impaired, which commonly seem geared towards older people.<sup>68</sup>

### Counselling and emotional support

Emotional support is crucial for people who are losing their sight—particularly working-age adults who are becoming less able to provide for themselves and their families. One interviewee told us that there is a real lack of specialist counselling delivered by qualified professionals.

Informal peer support interventions can complement such professional support. For example, RNIB Scotland’s ‘Looking Forward’ is a four-week peer support programme for people experiencing sight loss. The Macular Society also runs local groups across the country that offer practical and emotional mutual support. Experts told us that peer support interventions like these are both effective and sustainable.

## Older adults

### Mobility training and rehabilitation

Specialist mobility training and rehabilitation services are important for all visually impaired people, but are particularly vital for older people. A number of charities provide mobility and orientation training to support people to get out of the house, access services, and engage with their community. People with sight loss say that these services improve their safety, confidence and independence.<sup>69</sup>

Charities can provide access to alternative mobility and rehabilitation techniques that are not available from statutory providers. For example, the Structured Discovery approach, a nonvisual method of learning to travel, helps to build people’s confidence and problem-solving skills; studies suggest that this may be more effective than conventional mobility training.<sup>70</sup> Charities like Visibility and the Macular Society train people in advanced vision rehabilitation techniques, such as eccentric viewing and steady eye strategy, to help them to make the most of their remaining vision. Visibility and Fife Society for the Blind also provide assessment and training in neuro vision technology to rehabilitate people with vision impairment following a stroke or brain injury.<sup>71</sup>

### Social activities

Community services such as befriending, social activity groups and day centres can have a transformative impact on older people’s quality of life. As well as increasing visually impaired people’s interaction with their peers and their local community, they can pick up on early warning signs if people are not coping well or experiencing depression. Experts emphasised that these types of activities are ‘*tried and tested*’ solutions to meeting the needs of visually impaired people—particularly older people who are vulnerable to isolation and loneliness. Many of the

best projects combine social interaction with other goals, such as increasing mobility. For example, Visibility's 'Go Active' project helps people to extend their comfort zone through group walks, cycling and skiing.

## Solutions to support systems change

As well as solutions that work with specific groups of visually impaired people, there is a need for solutions that target the social systems and support structures that impact their day-to-day lives. These include interventions to train frontline workers, build the evidence base, campaign and advocate to influence policymakers and the general public, and improve access to technology.

### Training for frontline workers

*'We need to up the game in terms of how we train staff ... Even people in caring professions are pretty poorly informed about people with sensory impairments.'*

John Paterson, Chief Executive, Scottish Council on Visual Impairment (SCOVl)

Training frontline workers can lead to significant improvements in the welfare of people with visual impairment. One charity that we interviewed provides training and leaflets for client-facing workers in health and social care, housing agencies, local restaurants and transport services. This increases workers' sensitivity to the impact of sight loss and gives them tips and tricks to support people. Another expert told us that simple screening tests could be rolled out across care homes to identify unrecognised sight loss. Others mentioned the need to raise awareness of children's needs amongst educational professionals through projects like RNIB's 'Insight Online' resources for teachers.

### A stronger evidence base

Research into the needs of visually impaired people and levels of provision can play an important role in improving services. A few interviewees were concerned about gaps in knowledge of service provision in Scotland. One pointed out that academics and charities often work in silos and *'we're not gathering a concerted evidence base'*. As charities seek to work closer together in order to meet the needs of their beneficiaries, there is an urgent need to improve the evidence base for their work and to spread good practice. For example, VisionPK, a charity based in Perth, has integrated the 'Seeing it my way' outcomes into its new service pathway. Staff use these to support individuals in identifying their desired outcomes, and then work with them to try to achieve these. Funders could support other organisations to learn from and adapt this approach.

### Campaigning and advocacy

Charities can increase the welfare of visually impaired people by campaigning on issues that affect their lives. Some campaigns are best targeted at local and national policymakers or manufacturers. For example, Guide Dogs has projects ranging from its 'Streets Ahead' campaign—which aims to remove objects on pavements—to its 'Safe and Sound' campaign—which seeks to ensure electric vehicles are not silent. Other campaigns can influence public opinion more broadly to change what people think about sight loss—by, for example, showing the public that it is not an inevitable part of ageing.

### Improved access to technology

There is an urgent need for solutions that help visually impaired people make the most of technology. New technologies have the potential to transform people's lives, but there are significant barriers and access issues. One expert told us that *'the use of technologies has made the biggest difference to people'*, but there is also widespread frustration that the pace of change has not been quicker. Some charities are running taster sessions and training programmes to acquaint people with digital technology. Perhaps cross-generational projects could help to bridge the technological divide, with young people helping older adults to increase their skills and confidence.

# CHARITIES AND FUNDERS

In this chapter we outline the work currently being done by voluntary sector organisations to support visually impaired people in Scotland. We then summarise the ways in which charities and funders can further this work.

## Charities supporting visually impaired people in Scotland

There are around 120 charities in Scotland working on visual impairment issues or with visually impaired people.\* Some of our interviewees felt that this charitable sector in Scotland is underdeveloped compared to other sectors, owing to the relatively low prevalence of sight loss and the geographical spread of those affected. A range of Scottish charities are working on visual impairment issues, but—as is typical in the charity sector—they are overwhelmingly skewed towards the smaller end of the income spectrum:

- 21 have an income of over £1m.
- 14 have an income of £100,000 to £1m.
- 20 have an income of £10,000 to £100,000.
- 65 have an income of under £10,000.

Most of the large charities are long-established, and most have a presence throughout Scotland or even across the UK. They include the Royal National Institute of Blind People (RNIB), The Guide Dogs for the Blind Association, the Macular Society, and Scottish War Blinded. Some charities, such as Sense Scotland and Deafblind Scotland, cover hearing impairment as well as visual impairment. One interviewee told us that these long-established charities tend to *'know the area and know what they have to provide'*. However, others see them as less nimble and responsive to user needs than smaller charities.

Underneath these large Scotland-wide charities are five regional societies for the blind, which have operated for decades. They typically provide statutory services in partnership with local authorities as well as a range of voluntary services. In recent years, some have given back their statutory contracts, citing concerns that the low level of funding would have diminished the quality of services and compromised the safety of staff. The local societies have historically had high reserves, giving them the flexibility to develop services without applying for grant funding. For example, VisionPK in Perth and Kinross has used its reserves in recent years to improve its services for children and young people.

Scotland also has a myriad of small charities helping people who have lost their sight. They typically provide services within local communities, and many of them are run by visually impaired people. For example, there are talking newspaper associations, magazine tape recording services, and social clubs (such as the Three Towns Visually Impaired Club and West Lothian Visually Impaired Bowlers). While these small charities lack the resources of their larger counterparts, many of them have strong connections within their communities and are able to respond quickly to changing needs.

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\* Based on analysis of OSCR data, using a keyword search of charities' objects, and excluding charities with no income, those operating outside Scotland, and those that are not delivering services.



## The role of charities

### Complementing statutory provision

*‘Charities have the potential to be game-changers because they can attract particular funding to put services in place that are not funded through statutory provision.’*

Mhairi Thurston, Lecturer in Counselling and Psychotherapy, Abertay University Dundee

Charities often deliver publicly funded services for older people and visually impaired people, and their work runs alongside that of the public sector. One expert we spoke to argued that as the state withdraws, *‘it’s not the charitable sector’s responsibility to step in’*. Our interviewees felt that the real value of the charitable sector is in providing services that wrap around more limited statutory provision. However, they also recognise that statutory services and charity activities often overlap in practice, especially as local authority budgets are shrinking. Charities that are funded to provide statutory services typically provide *‘added value’*, over and above what is council-funded.

### Increasing collaboration

*‘It is a very collaborative arena. Everyone’s very open-minded about working together.’*

Bob Ironside, Chief Executive, VisionPK

Visual impairment organisations are working together more and more—a promising trend that could help the sector to better meet the needs of visually impaired people. The Scottish Council on Visual Impairment (SCOVl) brings together disability groups, charities, local authorities and professional organisations to promote collaboration and capacity-building. At a local level, charities often work together to refer people to each other or to deliver services in partnership. In Perth and Kinross, for example, VisionPK hosts an outreach worker from Scottish War Blinded on its premises and makes use of resources from larger charities, such as Guide Dogs and RNIB Scotland, to provide specialist advice and training.

However, the sector could still become better at collaboration. One interviewee emphasised that many organisations have been *‘thrown together’* by the See Hear strategy (page 6), but this is not the same as deeper collaboration. Another called on the sector to *‘end the battleground mentality’* in order to *‘find common ground and have a conversation about what we all do as a sector’*.

## The role of independent funders

### Funders already working on visual impairment in Scotland

Very few funders target visual impairment services in Scotland. Notable exceptions are the RS Macdonald Charitable Trust and the Agnes Hunter Trust. Some Scotland-only and UK-wide funders give grants in this area as part of their wider portfolio. For example, the Big Lottery Fund is funding a five-year early intervention project delivered by RNIB Scotland and Visibility. The Robertson Trust funds a range of projects for people with physical health and long-term conditions, which could include visual impairment. There are also some small foundations and individual philanthropists providing financial support for sight loss services. For example, the Beatrice Laing Trust funds charities providing practical services to people with physical health issues and their families.

## Funding trends and questions for funders to consider

When funders are planning their strategies to address visual impairment, the priority solutions identified in the previous chapter could hold promise for funding. There are also some general questions that are worth discussing when formulating a funding agenda.

### **Do you want to focus on the largest group of people in need, or on smaller groups with specialist needs?**

Most people with sight loss in Scotland are aged over 65—this is by far the largest group in need of support. Services to meet older people’s needs are undoubtedly underfunded. However, the dominance of this age group can obscure the specialist needs of other groups. In particular, children who are born blind and their families can benefit from early intervention and intensive support to help them to thrive. Independent funders with limited means can have a significant impact by focusing on issues that have been neglected by other funders. This way, it is also possible to play a convening and facilitating role, bringing together experts and people who work in the sector for focused discussions.

### **Is there a danger of losing specialist provision with the move towards joint sensory services?**

The integration of sight loss and hearing loss services makes sense in some cases. For people with low levels of both sight and hearing loss (particularly common amongst older adults), integration has clear benefits: it can lead to more streamlined services and better identification of ‘hidden needs’. But there is widespread anxiety in the sector that joint sensory approaches could lead to lower quality services or a loss of specialist provision. Many argue that sight loss is a unique experience that is distinct from hearing loss on a number of levels. As one visually impaired interviewee explained: *‘There is something very particular about acquired sight loss. Culturally, the fear that is associated with going blind is stronger than going deaf.’* Independent funders should consider whether there is a need to fund specialist services for visually impaired people to complement the joint sensory service approach being promoted in Scotland.

### **Should more funding be put into influencing social systems and support structures?**

As this report explains, there are social systems and support structures that impact the lives of people with sight loss. Funders can fund work to change these systems so that they better meet people’s needs. For example, they could fund charities to provide training for frontline workers who interact with visually impaired people; fund charities to work with manufacturers to ensure that new technologies work for visually impaired people; or fund charities to campaign to change policy or challenge misperceptions about sight loss. These interventions can have a longer-lasting impact than interventions that focus on meeting immediate needs.

### **Should more emphasis be put on collaboration?**

Many sector experts are concerned that charities are not collaborating as effectively as they could be. One interviewee suggested that independent funders could play a role in creating *‘a level playing field in which competition is replaced by cooperation’*. Collaboration as an end in itself is not worthwhile. The costs of collaboration—time, money and opportunity costs—mean that it should only be undertaken where there is a clear purpose and demonstrable benefits. Funders should not force collaboration upon charities, but they may wish to consider how to encourage purposeful collaboration that makes the sector more effective at meeting the needs of people with visual impairment.

# CONCLUSION

Visually impaired people need not lose out in life, and with the right support they can play a full and active part in Scottish society. But this support is often over-stretched and the situation is getting worse: sight loss is becoming more common, and public sector funding is becoming more scarce, leaving a great deal of unmet need. Fortunately, there is strong momentum for change, as the sector looks at increased collaboration and new ways of working, while new technologies have the potential to transform lives.

## Key findings

We have explored the landscape for charities working on visual impairment in Scotland, and discussed priority needs and solutions for visually impaired people. In summary, our key findings are:

- The needs of visually impaired people vary widely for different age groups. Solutions should be targeted around a detailed understanding of these distinct needs. Priority solutions include:
  - specialist habilitation and support for the families of pre-school children;
  - support at times of transition and with classroom technology for school-aged children;
  - work with employers, peer support, counselling and emotional support for working-age adults; and
  - mobility training, rehabilitation and social activities for older adults.
- Projects that tackle broader social systems and support structures can also have a huge impact on the welfare of visually impaired people. These include interventions to train frontline workers, improve access to technology, and build the evidence base, as well as campaigning and advocacy to influence policymakers and the general public.

## Recommendations

We have three key recommendations:

- Funders should fund interventions that meet the needs of different age groups. This means balancing provision for older adults—who form the majority of people with visual impairment—with services to support younger people, who have their own distinct needs.
- Funders should help to strengthen the social systems and support structures for visually impaired people at this time of shrinking state budgets.
- Funders should support solutions that have the greatest impact on people’s lives, and that follow the best practice principles of being specialist, person-centred and social.

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